

Advance Care Planning for Patients with End-stage Kidney Disease: A Local Perspective

Wendy Gibson *Clinical Nurse Consultant* and Bharati Mehta *Senior Social Worker* - Renal Supportive Care Nepean HUB Western Renal Services

Patients with end-stage kidney disease (ESKD) experience a high symptom burden and increased morbidity and mortality rates compared to those with other diagnoses. Many older patients, especially those with multiple comorbidities, may not achieve any improvement in function or longevity with Renal Replacement Therapy.¹

To help reduce family/patient pre-conceptions, anxiety levels and make care patient centred, it is imperative that a timely Advanced Care Plan (ACP) discussion is held prior to any approach towards the end of life (EOL). An ACP, is a document to inform physicians about a patient’s wish about their ceilings of care, when they can no longer speak for themselves or make their own medical decisions. They are sometimes called a ‘living will’.³

The Renal Supportive Care (RSC) movement through the Agency for Clinical Innovation (ACI) recognised that patients on both Renal Replacement Therapy (RRT) Pathways and Conservative Non-dialysis Pathway (CNP) had low rates of completed Advanced Care Plans (ACP) which is a Key Performance Indicator within RSC.²

Local RSC Teams were asked to address this situation within their own Local Health Districts by developing a pathway or framework (see figure 1.0). Which would allow either the patients nephrologist or the RSC team, be responsible for facilitating the ACP discussion with a patient.

RSC team already supported CNP patients to have an open and thoughtful ACP discussion after referral to the RSC Clinics as part of their conservative care journey. RRT patients had no set pathway to having an ACP completed outside of that done by their nephrologists or general practitioner prior to this framework.

The Nepean RSC Team formed a committee to develop mechanisms within a framework that addressed the lack of ADP for not only for RRT patients, but with individuals that have decided on a CNP. In 2016 local statics concluded that only 21% of RRT and 20% of CNP patients had a ACP.²

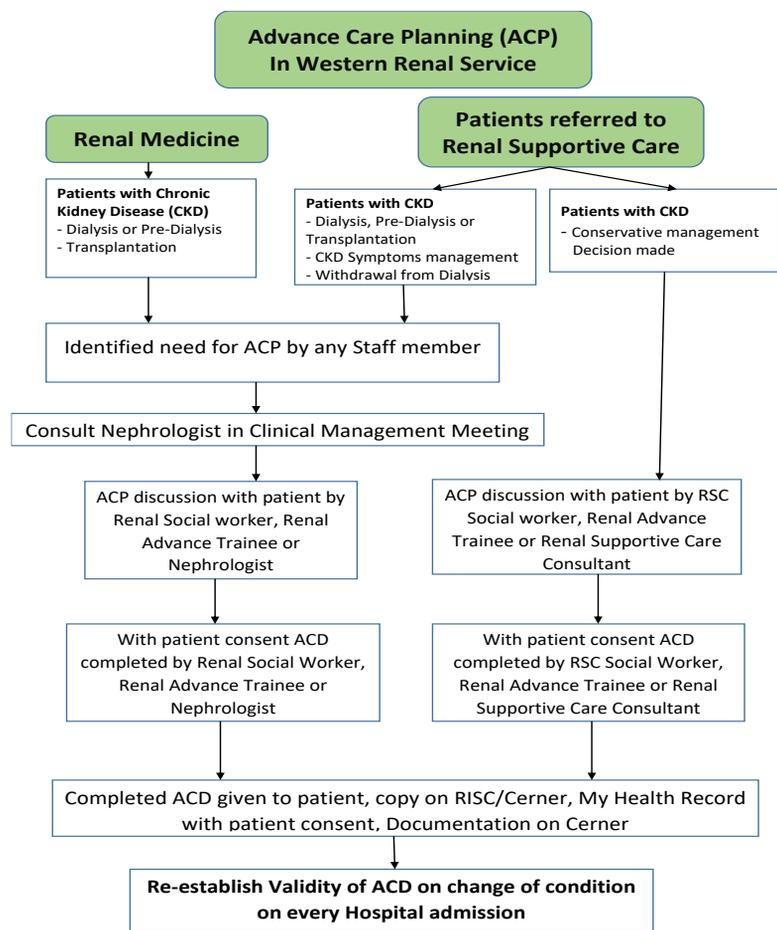


Figure 1.0 Advanced Care Planning (ACP) In Western Renal Sydney Framework by B.Mehta

In consultation with key stakeholders including the nephrologists, nursing staff, social workers and team members of the Nepean RSC; the RSC social worker, commenced a framework for referral of appropriate patients to the RSC team for ACP discussions.

During the development of the framework multiple consultations took place between the ACP committee members and nephrologists. In the final version of the framework the RSC teams would only undertake ACP discussions with RRT patients with the expressed permission of the nephrologist. Patients referred to RSC Clinics on a CNP would automatically have an ACP discussion.

As part of the response measures coming from the development of the ACP framework the RSC team provided:

- Education to nursing/medical/allied health about differentiation of ACP and a Medical Resuscitation Plan
- Education around the legal complexity of Medical Resuscitation Plans and ACP
- Worked with stakeholders to identify who had responsibility for formalising ACP and Medical Resuscitation Plans
- Developing communication skills for RSC team members

The RSC team have anticipated through this process that we would need to consider developing:

- a Nurse Champion role within each dialysis unit
- considerable educational interventions will be required for all renal staff in the foreseeable future with ongoing support from the RSC team

Future planning and development of this framework will encompass education strategies of providing Local Health District driven in-services about the process of ACP discussions, EOL discussions and appropriate patient centred care. This development will encompass ideas of empathy, compassion and dignity with the legal aspects of delivering patient centred care associated with Advanced Care Planning and Supportive Care.

1. Verberne, W. R., Dijkers, J., Kelder, J. C., Geers, A. B. M., Jellema, W. T., Vincent, H. H., ... Bos, W. J. W. (2018). Value-based evaluation of dialysis versus conservative care in older patients with advanced chronic kidney disease: a cohort study. *BMC Nephrology*, 19(1). doi: 10.1186/s12882-018-1004-4
 2. NSW Renal Supportive Care Site Report December 2019 Agency for Clinical Innovation
 3. My Health Record NSW Health : Managing your record